

**REPORT TO THE TWENTY-SECOND LEGISLATURE
STATE OF HAWAII
2004**

**PURSUANT TO SECTION 321-291, HAWAII REVISED STATUTES
REQUIRING THE DEPARTMENT OF HEALTH TO GIVE AN
ANNUAL FINANCIAL REPORT FOR THE
NEWBORN METABOLIC SCREENING SPECIAL FUND**

**PREPARED BY:
STATE OF HAWAII
DEPARTMENT OF HEALTH
DECEMBER 2003**

EXECUTIVE SUMMARY

The Hawaii Newborn Metabolic Screening Program (NBMSP) is administered by the Hawaii State Department of Health. NBMSP has statewide responsibilities for assuring that all infants born in the State of Hawaii are tested for phenylketonuria (PKU), congenital hypothyroidism, and other diseases that are added to the screening panel. This program tracks and follows up on infants to assure satisfactory testing and to assure that infants with the specified diseases are detected and provided with appropriate and timely treatment. The objectives are to prevent and ameliorate the effects of handicapping conditions that are identified through the administration of newborn screening and diagnostic testing.

In 1996, legislation was passed, H.R.S. §321-291, which established a newborn metabolic screening special fund which is used for operating expenditures, including, but not limited to, laboratory testing, follow-up testing, educational materials, continuing education, quality assurance, equipment, and indirect costs.

The Hawaii Administrative Rules, Chapter 11-143, revised and adopted on November 20, 2003, reflect the following changes:

- Expansion of the newborn metabolic screening testing battery to include tests for:
 - Phenylketonuria (PKU)
 - Congenital Hypothyroidism
 - Galactosemia
 - Hemoglobinopathies
 - Congenital Adrenal Hyperplasia (CAH)
 - Maple Syrup Urine Disease (MSUD)
 - Biotinidase Deficiency
 - Amino Acid Disorders
 - Fatty Acid Oxidation Disorders
 - Organic Acid Disorders
 - Urea Cycle Disorders

- Changed the newborn screening fee from \$27.00 to \$47.00 per specimen collection kit beginning September 1, 2003. The fees will be deposited in the newborn metabolic screening special fund, which will pay for the following costs:
 - Centralized laboratory testing for the thirty-one disorders;
 - Repeat testing for initial specimens collected at less than 24 hours of age;
 - Confirmatory testing up to the point of diagnosis if specimens are sent to the designated testing laboratory;
 - Specimen collection and handling;
 - Overnight mailing costs of the initial specimens to the testing laboratory;
 - Newborn Metabolic Screening Program staff salaries and fringe benefits;
 - Contracted nutritionist, pediatric metabolic specialist; pediatric endocrinologist; and pediatric hematologist services;
 - Tracking of infants, screening costs for the uninsured indigent; and the administration of the statewide newborn screening system;
 - Continuing education;
 - Educational materials;
 - Quality assurance;
 - Equipment
 - Indirect costs
 - Administrative overhead

The attached financial report for FY 2003 (July 1, 2002 to June 30, 2003), required by § 321-291, HRS, identifies all fund balances, transfers, and expenditures made from the newborn metabolic screening special fund and the purposes of each expenditure.

Report on Non-General Fund Information
for Submittal to the 2004 Legislature

Department: HEALTH

Date:

November 10, 2003

Prepared by:

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Phone:

733-9062

Name of Fund: Newborn Metabolic Screening Special Fund

Legal Authority: Section 321-291, HRS

Fund Type (MOF): B

Approp. Acct. No. S 302 H

Intended Purpose:

This fund is to be used for payment of its lawful operating expenditures, including, but not limited to laboratory testing, follow-up testing, educational materials, continuing education, quality assurance, equipment, and indirect costs.

Current Program Activities:

The Newborn Metabolic Screening Program (NBMSPP) has statewide responsibilities for assuring that infants born in the State of Hawaii are satisfactorily tested for 31 disorders which can cause mental and growth retardation and even death, if not detected and treated early in the newborn period. NBMSPP tracks and follows-up on infants to assure that the infants with the specified diseases are detected and provided with appropriate and timely treatment. Other activities are assessment, quality assurance, continuing education, and standard setting.

Financial Data		
	FY 2003	FY 2004
Beginning Cash Balance	362,580.40	325,345.53
Beginning Encumbrances	68,310.86	113,875.39
Revenues	509,202.80	
Expenditures	512,656.19	
Transfers (List Each Transfer by JV# and Date)		
JV #JM2673 - 12/11/02	33,781.48	
Net Total Transfers	33,781.48	
Amount Derived from Bond Proceeds		
Ending Cash Balance	325,345.53	
Amount Required for Bond Covenants as of 7/1/02		
Amount held in Certificates of Deposit, Escrow Accounts, or Other Investments as of 7/1/02.		

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PURPOSES OF EACH EXPENDITURE FOR FY 2003

I.	Newborn Metabolic Screening Program Personnel Costs	
A.	Payroll (3 FTE)	\$190,944.95
B.	Car Mileage	774.79
II.	Implementation of newborn screening system utilizing a centralized laboratory	
A.	Oregon State Public Health Laboratory for comprehensive newborn screening testing services	269,155.91
B.	FedEx courier services to deliver specimens overnight to the newborn screening testing laboratory	29,286.49
C.	Two New computers	3,684.74
D.	Laser Jet printer	1,499.95
E.	Tyvek envelopes for the mailing of specimens to the centralized laboratory	1,935.46
F.	Fax machine maintenance	361.30
G.	Newborn screening testing for the indigent/uninsured	100.25
III.	Staff education	
A.	2002 Newborn Screening and genetic Testing Symposium, Phoenix, Arizona, 11/2-7/02	1,140.00
B.	Improving the Efficacy and Effectiveness of Tandem Mass Spectrometry Screening, Berkeley, California, 1/12-14/03	936.70
C.	Subscription to <u>PKU News</u>	18.00
IV.	Parent education on newborn screening	
A.	MSUD Foodlist booklets	50.00
V.	Air and ground transportation for endocrinologist services on the Neighbor Islands	5,585.65
VI.	Nutrition services for clients with metabolic disorders	7,182.00
	TOTAL	<u>\$512,656.19</u>
	JV #JM2673: Assessments for central services and administrative expenses for FY 02	33,781.48

BEGINNING ENCUMBRANCES FY 2004

Oregon State Public Health Laboratory	\$75,010.22
Nutritionist services	1,164.00
Fax machine maintenance	65.36
Other supplies	.81
Newborn screening services for the indigent/uninsured	635.00
Assessments for central services and administrative expenses for FY 03	37,000.00
TOTAL	\$113,875.39